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## Navigating the new normal: accessing community and institutionalised care for dementia during COVID-19

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### ABSTRACT

**Objectives:** Little is known about how community services and institutional care settings have adapted to providing support since the COVID-19 pandemic. The aim was to explore how these care services have adapted during the pandemic in the UK and are providing care to people living with dementia (PLWD) and carers.

**Method:** Semi-structured telephone interviews were conducted in June and July 2020 with 16 purposefully sampled unpaid dementia carers. Participants were asked about their experiences of accessing care services since the lockdown, and whether they were beneficial, if accessed at all.

**Results:** Three themes were identified: (1) Impacts of no activities; (2) Difficulties accessing care during the pandemic; (3) Remote vs. face-to-face support. Loss of access to previously enjoyed activities and having had to shield for many PLWD is suggested to have led to severe physical and cognitive deteriorations, advancing the dementia. Where remote support was available, this was helpful to some, but did not replace the benefits of face-to-face support. Where PLWD were residing in a care home, carers had very limited remote access.

**Conclusions:** This is the first study to explore the impact on carers both from a community and institutionalised care angle. Few care services have adapted to providing remote support. With the vaccine taking time to be accessible to everyone, it is vital for organisations to work closely with carers and PLWD to adapt services to provide much needed support.

### ARTICLE HISTORY

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### KEYWORDS

Dementia; COVID-19; community care; care homes; digital technology

### Introduction

Worldwide, over 50 million people are estimated to live with dementia (Alzheimer's Disease International (ADI), 2020). However, many more people are affected indirectly by dementia, by caring for a relative or friend with the condition. In the UK, unpaid carers are the largest dementia care workforce and save £13 b per year to the health and social care economy (Alzheimer's Society, 2014).

The COVID-19 pandemic has caused severe changes to how care, both community-based and institutionalised, is accessed, if at all (Giebel, Cannon, & Hanna, 2020; Verbeek et al., 2020). Although literature on the effects of the COVID-19 outbreak on dementia and dementia care is very limited to non-existent, some emerging evidence indicates already that people living with dementia (PLWD) experience faster symptom deterioration during the pandemic (Canevelli, Valletta, & Toccaceli Blasi, 2020). This might be linked to a lack of stimulation by being unable to enjoy previous social activities, and by being restricted to an environment – either the own home or a room in a care home. This supports identified concerns by unpaid carers and PLWD in the UK shortly after a nationwide lockdown was imposed on the 23rd of March. Giebel, Cannon, and Hanna (2020) found that participants were concerned about the future and how social support and care can be provided to PLWD during the pandemic. Many faced sudden withdrawals of social support services and had to make risk management decisions about home carers entering the home (Giebel et al., 2020).

Care homes have been particularly affected by the COVID-19 pandemic, with currently over 19,000 care home residents in England and Wales, and over 22,000 across the UK, having passed away from COVID-19 (Office for National Statistics (ONS), 2020). Whilst government responses were late in supporting the care home sector, care homes had no guidance on how to provide adequate support during the pandemic. Thus, whilst all care homes shut down to any outsiders since March, each care home had to come up with their own methods on how best to support residents, and how to provide physical, mental, and social activities, if any. This also meant that family carers have been unable to see their relatives face-to-face over a prolonged period of time. Whilst it is known that social engagement is linked to improved well-being in people with dementia (Martyr et al., 2018), it remains unclear to what extent the lack of interaction has affected residents and how carers have been affected by these lockdowns.

The aim of this study was to explore how the pandemic has affected accessing community-based and institutionalised dementia care during the pandemic. For this purpose, this study followed up on unpaid carers who were interviewed shortly after UK nationwide lockdown (Giebel, Cannon, & Hanna, 2020). Considering that COVID-19 is staying for the foreseeable future, and impacting on vital social interactions and face-to-face meetings between people, regardless of vaccination, it is important to understand how services can be adapted best to continue supporting the needs of some of the most vulnerable in our society.

## Methods

### Participants and recruitment

Unpaid (current and former) carers aged 18+ who were living in the community were eligible to take part. Participants were originally recruited from various social support service and third sector organisations via convenience sampling, using newsletters and social media, and contacting people who were members of organisations individually via email or telephone. Participants in the original and in the follow-up study were selected in order of expressing an interest. This was due to the time-sensitive nature of the topic under investigation, and leaving too long a period of data collection would have resulted in capturing experiences based on different public health restrictions imposed. This is because restrictions in the UK have been changing fairly quickly. The aim of the baseline interviews was to assess how PLWD and unpaid carers had been affected shortly after lockdown was imposed and how social support services were providing care a few weeks after lockdown. This follow-up study solely focuses on a sub-sample of unpaid carers who have completed an interview a few months later, to understand how unpaid carers are now navigating both community-based care and ILTC for dementia after some time had passed since initial lockdown and the start of the pandemic. A sub-sample of the originally interviewed 50 participants was purposefully selected to have unpaid carers in the follow-up interviews, including variation in terms of care home experience and community care experience.

We obtained ethical approval from the [blinded] [ID 7626].

### Data collection

Data were collected between June and July 2020. Semi-structured interviews were conducted over the phone and audio-recorded and subsequently transcribed. At the beginning of the interviews, verbal informed consent was obtained. Participants were asked about their experiences in the past few months since the last interview, whether their situation had changed, whether support services had adapted, and whether they felt they received all the support they needed (see Appendix 1 for topic guide). The topic guide was developed with a person living with dementia, unpaid carers, service providers, and clinicians to ensure that the questions we asked were relevant to the situation and aims.

### Data analysis

Following transcription, each transcript was assigned to two separate researchers for coding using descriptive, thematic analysis (Braun & Clarke, 2006). This involved researchers to read through each transcript and highlight quotes as codes. Where these emerged repeatedly, researchers formed ideas for themes prior to discussing these with the team. When all transcripts were double-coded, the researchers met to discuss the codes inductively, generating initial themes, which were then reviewed and defined collectively. One coder was an unpaid carer, ensuring public involvement in the stage of analysis also. All members of the research team agreed the final themes, including a person living with dementia, unpaid carers, service providers, clinicians, and academics, everyone jointly interpreting the findings.

## Results

### Participant characteristics

Sixteen unpaid carers took part in the follow-up interviews. The majority of participants were female ( $n = 15$ , 93.8%) and aged  $55.3 \pm 6.2$  years [36–62]. Most carers were the child of the PLWD ( $n = 10$ , 62.5%), and the remainder were spouses. Most carers lived separate from the PLWD ( $n = 9$ , 56.3%). Dementia subtype of the PLWD being cared for by the participant (carer) varied from Alzheimer's disease dementia ( $n = 8$ , 50%) to vascular dementia ( $n = 2$ , 12.5%), with three (18.8%) reporting young-onset dementia without a specific dementia subtype. IMD quintiles showed that carers lived in a mix of disadvantaged and more affluent neighbourhoods. Participant demographics are shown in Table 1.

### Qualitative analysis

Thematic analysis identified four overarching themes: (1) Impacts of no activities; (2) Difficulties accessing care during the pandemic; (3) Remote vs. face-to-face support.

### THEME 1: Impacts of no activities

#### Physical health

Carers described physical deteriorations of PLWD as a result of having to stay at home and no longer attending social activities and previously enjoyed hobbies. Some people with dementia were apparently very bored and slept a lot, as there was nothing to do. With older adults with dementia also shielding, and thus not necessarily going to the supermarket or engaging in other basic tasks outside the home, they were even less likely to move.

**Table 1.** Demographic characteristics of carers.

	Carers ( $n = 16$ )
<i>N</i> (%)	
Gender	
Female	15 (93.8%)
Male	1 (6.3%)
Ethnicity	
White	13 (81.3%)
BAME	3 (18.3%)
Relationship with PLWD	
Spouse	6 (37.5%)
Adult child	10 (62.5%)
Living with PLWD	
Yes	7 (43.5%)
No	9 (56.3%)
Dementia subtype	
Alzheimer's disease	8 (50%)
Mixed dementia	2 (12.5%)
Vascular dementia	2 (12.5%)
Lewy Body dementia	0
YOD	3 (18.8%)
Other	1 (6.3%)
IMD quintile <sup>a</sup>	
1 (least disadvantaged)	1 (6.3%)
2	6 (37.5%)
3	1 (6.3%)
4	2 (12.5%)
5 (most disadvantaged)	4 (25%)
Internet access	
Yes	15 (93.8%)
No	1 (6.3%)
Mean (SD), [Range]	
Age	55.3 ( $\pm 6.2$ ) [36–62]
Years of education	15.8 ( $\pm 3.4$ ) [11–22]

<sup>a</sup>Missing data for three carers (IMD).

'he's sleeping in more, where he used to get up with me early you know to take, I used to take the kids to school and he used to be up by then but he goes to bed later so he's obviously getting up later and because he's got nothing to get up for, there's no really routine.'

**Female carer (daughter), ID24**

### *Faster progression of dementia symptoms*

Carers described faster symptom deterioration (including cognitive and behavioural symptoms) since social support services were stopped in March and since shielding and lockdown commenced. Carers attributed these faster declines in independence and general cognitive abilities to the lack of social contact and mental stimulation, with no routine any longer of seeing peers and engaging in activities. Instead, all PLWD are doing is stay at home.

'he was deteriorating but once lockdown started then he withdrew even more, he was quite withdrawn anyway but he withdrew even more and he literally just took to his bed and just laid in the foetal position. His habitual behaviours became worse, his mobility changed his behaviour changed I had to feed him because he could feed himself independently, I'd feed him and then he started to have falls' **Female carer (spouse), ID23**

'she'd only been in there [care home] for 12 weeks when lockdown happened and she had done marvellously. She had settled amazingly and yes I don't think it's anything to do with lack of care or lack of support or lack of expertise. It's not just her visits that stopped, none of the activities have been able to be maintained because all those outside people weren't allowed to go in.' **Female carer (daughter), ID35**

## **THEME 2: Accessing care and connecting with relatives during the pandemic**

### *Patchy service provision*

Variation was noted in terms of the quality and quantity of service provision offered to carers and PLWD during the time of COVID-19. Where support for dementia was provided, the respondents felt reassured that someone was available to support them if they needed it. However, contrasting reports suggested that others were offered little or no care support. Where just one phone call was offered to the carer, it was noted that the timing of the phone call did not necessarily coincide with a time where they needed the support most.

'it's just that they [memory team]ve been there to support us if things have been getting worse. It's like because I could speak to them, they upped his medication which helped so and it's just knowing that there was somebody there that if I did have an issue I could just ring but also the doctors been ringing on a weekly basis to make sure we're all right and managing' **Female carer (daughter), ID01**

'there has been no outside support at all erm other than we did have 1 phone call from the Care Navigators... so maybe about 3 or 4 weeks ago just to see how my mother in law was getting on and whether she needed anything which was really lovely but possibly a little late' **Female carer (daughter-in-law), ID42**

### *Preparing for COVID-safe face-to-face services again*

One carer was based in Leicester, which experienced a sudden second lockdown. In her case, the previously enjoyed weekly support group was preparing to provide COVID-safe socially distanced face-to-face support again in a few weeks' time when

the second lockdown happened. This has taken away some hope and left the carer, and the PLWD, struggling more.

'they'd spoken to my mum about it on the weekly calls that she gets from the woman that runs the groups. She said that they'd been in discussions with her management about how they were actually going to logistically do it you know because obviously they have transport that people can access so they were trying to figure out how many people can they safely transport in on a minibus and then how would the room be laid out and how many people could you actually have in that room to be socially distanced and to make sure that people were safe.' **Female carer (daughter), ID38**

### *Accessing care homes due to increased care needs*

Some carers needed to find a care home place for their relative with dementia, as they had deteriorated throughout the lockdown period. However, due to care home closures to the outside, finding care home places was very difficult to impossible, which meant that unpaid carers had to continue providing increased levels of care to the PLWD in the home environment. Some carers were only able to get a care home place far away, but took the opportunity as the only available option.

'she [PLWD] got that bad I had to put her in a home because I couldn't cope with her and my mum and dad because she wouldn't come out she just wanted to stay at home and didn't want to come to the groups and mix, so I can see the impact of going out to groups and staying in because she went downhill' **Female carer (daughter), ID01**

'the carers had to increase the care package and it was just not sustainable in the home anymore because he needed 24 hour care, so I got him I got him in [a care home] really quickly because obviously it was an emergency and he's now in a care home 25 miles away so it's a 50 mile round trip, because obviously a lot of the care homes weren't actually taking people in because of the incidences of COVID' **Female carer (wife), ID23**

Some care homes asked family members to pay inflated fees since the pandemic to account for additional measures put in place to support the needs of the resident, putting added financial strain on the carers.

'from a financial point of view yes it's hit us really hard... whilst [PLWD] has been in [care home] obviously he was assessed for continuing health care and he has been awarded the continuing health care so hopefully there won't be any top up fees or anything like that but then top up fees I don't know where they're going it from because there's not much coming in.... I did get a bill for 12 hundred pound from the care home on Saturday but I think it's just cross over of everything and I don't think I should have really had it' **Female carer (wife), ID23**

### *Staying in contact with relative in care homes*

Some carers described their experiences of staying in contact with their relative residing in a care home. Some care homes had adapted to providing remote contact between residents and family members, by connecting via what's app or providing regular phone calls.

'The care homes been absolutely brilliant you know what I mean they've kept me informed at all times. I'm able to ring on a daily basis if I want to check because especially at the height of the pandemic when we were worried about care homes actually getting the virus and they were really good. I could ring and speak to the manager.' **Female carer (wife), ID26**

'They set up WhatsApp calls and video calls. So I've been able to talk to mum every day sometimes you can't get through because obviously all the relatives are ringing on the same number.' **Female carer (daughter), ID35**

However, other care homes were delayed in providing remote connection between residents and their family members, and one carer had the additional emotive burden of her relative being infected with COVID-19 in the care home. This resulted in the care home no longer providing the limited face time remote support.

'But then since lockdown I wasn't able to go and that had an impact on me and her because I couldn't see her and it took them a while to set up Facetime and what have you anyway when they did I spoke to her on the phone on Facetime and the difference in a matter of weeks was unbelievable she really went downhill and then sadly she got the COVID and then I couldn't see her because of the way she was they couldn't Facetime me because of dignity and what have you.' **Female carer (daughter), ID01**

Other carers have had more face-to-face contact with their relatives with dementia, although by adhering to various social distancing measures such as meeting through a window or sitting apart wearing face masks.

'So what we have been allowed to do is to go and stand by those windows and speak to the residents inside. They have those top opening windows so they open the window so that we are physically remote from each other but we can hear each other through the open window. So I've been popping down just for sort of 10/15 minutes whenever it's not chucking it down with rain and standing in the car park and initially that, mum found that very stressful as well the first time she nearly collapsed in the same way she did on the first video call, just her blood pressure goes a bit nuts.' **Female carer (daughter), ID35**

'I have to wear a face mask and they will provide it and it's outside, we're not inside the building we're in the garden outside. There's a wall that separates me and my husband.' **Female carer (wife), ID26**

### THEME 3: Remote vs. face-to-face support

#### *Delays in or no access*

Not everyone has been accessing social support since lockdown, either face-to-face or remotely. Where people have accessed remote support, this was often delayed in getting set up, and many participants were still waiting for this to be organised and uncertain about what was happening.

'I got a message yesterday from someone from the [dementia care organisation] and they said they're thinking of setting up a virtual singing class and my dad went there, I mean I don't know he will, he likes to sing, he knows the words to every song but he's not, so he might have a go I've got a laptop so, I will set it up for him and see' **Female carer (daughter), ID24**

Carers also noted that where remote support existed, PLWD sometimes faced difficulties recognising previously familiar faces, rendering this form of adapted support unsuitable for their needs. Similarly, phone-based support was of little benefit to PLWD.

'all the groups and everything stopped so they'd gone from seeing each other every day, twice a day at all the different groups to actually nothing and then you see when COVID when the lockdown came in we facetimes and everything and he could still, he still knew them but then as times gone on he's not wanted to, when we facetime he's who's that who's that' **Female carer (daughter), ID01**

Some PLWD were unable to make use of virtual remote support due to other impairments, such as vision impairments. This left PLWD struggling to access any remote support.

'he's started an exercise class online but because of his visual impairment there was no way, that would have been more frustrating than beneficial, we came to that conclusion.' **Female carer (daughter), ID44**

#### *No replacement for the real thing*

Where carers and PLWD have been able to access remote social support, they stated they benefitted from this, being able to stay in touch with their peers and stay up-to-date with what is happening in their friendship circles. However, they also stated that remote support cannot effectively replace face-to-face meetings and interactions.

"we certainly use them [video calls] a lot more and the Zoom definitely...but it's not quite the same as in person is it, and I know you can see somebody on a screen but it's not quite the same as sitting down and having a cup of coffee and a good chat is it really" **Female carer (spouse), ID36**

#### *Technology issues*

Some carers noted that they had to set up the computer tablet for the PLWD they cared for, to enable contact with their peer support groups. Carers were uncertain if their relatives with dementia would be able to join these online meetings without their help.

'he would probably 'cause he doesn't, he's never been into technology really even before this. So if I'd have set it up for him he'd have been quite happily have a you know a little conversation'

**Female carer (daughter), ID24**

'he [PLWD] also struggles we've noticed with understanding using like a zoom, my brother will set up zoom and we can zoom and I've noticed he has certain faces he uses when he's finding a way to answer a question he doesn't understand' **Female carer (spouse), ID04**

### Discussion

This is one of the first studies to show how community and institutionalised dementia care services have adapted during the COVID-19 pandemic and the impact this has had on the lives of PLWD and carers. Carers reported mixed experiences of accessing support during the pandemic, with most having faced sudden removal of any type of support.

The sudden removal of previously enjoyed activities and services is believed to have led to faster deterioration of dementia symptoms and physical impairments. In earlier interviews, carers already expressed a fear of this posing a significant problem (Giebel, Cannon, & Hanna, 2020) which only a few months later has been confirmed by our follow-up interviews. Emerging evidence corroborates this notion, as cognitive and behavioural symptoms have been found to deteriorate faster since the pandemic in PLWD (Boutoleau-Brettonnière et al., 2020; Canevelli, Valletta, & Toccaceli Blasi, 2020). In addition, evidence from Spain from March suggests that older adults with mild cognitive impairment/mild dementia overall reported good quality of life, but many continued staying physically active. In the UK however, walks were restricted to once a day for a substantial period of time, and those classed as vulnerable (older adults and those with underlying health conditions) were told to shield from the 16th of March until the 1st of August. Considering the importance of

physical activity (Aubertin-Leheudre & Rolland, 2020), it is unsurprising that carers and PLWD have reported physical deteriorations since the lockdown commenced. Public health restrictions linked to faster dementia and physical health deteriorations is counterproductive to keep the most vulnerable of our society safe and healthy. This can lead to greater need for care home placements, which are, particularly in the current climate, environments that PLWD would want to avoid, due to increased COVID-19 infection risk and diminished activities to reduce transmission risk.

Both community and ILTC services appeared to have only slowly adapted to the new normal with few having recently started to provide some form of remote support via digital technology. However, many PLWD in the more advanced stages and older PLWD are found to be unfamiliar with technology and the Internet, and would not have been able to access remote support without their unpaid carer. This is reflected in generally high levels of digital illiteracy amongst older adults (Hargittai, Piper, & Morris, 2019). Where remote support was offered though this did not suffice to PLWD and carers, as it did not replace face-to-face meetings. Social interaction is vital for well-being (Lee, Boltz, Lee, & Algase, 2017), so that not only remote support and access to it needs to be significantly improved and supported, such as for example with Cognitive Stimulation Therapy for dementia during the pandemic (Cheung & Peri, 2020). Face-to-face meetings also need to be started up again in a safe and socially distanced way, where possible, depending on individual's circumstances.

Similar to community-based services, care homes have adapted very little to enable remote linkage between residents and family members so far. With care homes having been closed off to the general public until recently, the precise effects on care home residents are still unknown. Where remote support was available, some carers praised however how staff were adapting to providing Facetime calls. Considering how vaccination rollout across the UK has taken place from early December onwards, and data collected between June and July 2020, it is important to explore how care homes are linking up with relatives given these changes. Whilst remote support was found to be helping to connect with family and peers to some extent both in care homes and in the community, remote support was no replacement for real social contact and the benefits that social engagement provides (Hackett, Steptoe, Cadar, & Fancourt, 2019). Recent evidence from the Netherlands has highlighted the advantages that re-opening care homes in a safe format can have on residents (Verbeek et al., 2020). Potential negative effects of public health restrictions are likely further exacerbated by increased staff shortages and limited personal protective equipment in ILTC settings during the pandemic, as evidenced in the US for example (Xu, Intrator, & Bowblis 2020). It is crucial for residents to see their family members again, and for research to examine the full impact of care home closures on the lives of residents. It is equally important though for unpaid carers to receive more opportunities for respite care where they are providing care for a relative with dementia in the community, given the lack of social support services leading to increased hours of unpaid care.

Whilst this study benefits from following up unpaid carers who were first interviewed shortly after nationwide lockdown measures were imposed, this study has some limitations which need to be considered. Only five carers had experiences of ILTC during the pandemic, with other participants sharing their experiences of community care and living. However, the benefit of this sample is that some of the unpaid carers had previous experiences of community-based care provision throughout the

pandemic and pre-pandemic, thus offering a unique opportunity to gather information on how some carers have navigated both during the pandemic – community-based care and ILTC. With each care setting (community, care home) representing different challenges, having carers with both experiences involved in this study helps putting the experiences of either setting in the context of one another. This is specifically the case as the pandemic seemed to have fastened the need for care home entry due to reductions in community care services, which is to the detriment of the person with dementia as home care is favoured over institutional long-term care (Rapaport et al., 2020). Although we purposefully sampled those carers with institutionalised care experiences from the original set of interviews, future research needs to explore the issues surrounding care home adaptations to enabling family visits and continued social engagement in more detail. Moreover, this study solely focused on unpaid carers, and it is crucial to capture the experience of PLWD themselves in future research.

## Conclusions and implications

Unpaid carers face continuous difficulties in accessing support for dementia during the COVID-19 pandemic, both for community-based services and by trying to connect with their relative with dementia in the care home. Community-based support provision needs to have clear guidelines on how support can be provided safely with a mix of face-to-face and remote services, to meet the needs of both PLWD and unpaid carers. Similarly, whilst further research is required to understand the full picture of how COVID-19 has impacted on the lives of care home residents and on unpaid carers' connectivity with residents, first findings from our study highlight the need for streamlined guidance on how care homes can enable continued social engagement between residents and family members and friends in a safe environment. Adapting community-based social support to the pandemic's public health restrictions is vital as faster deteriorations linked to those restrictions can lead to faster and increased need of care home placements. Although findings are based on UK services, the pandemic has impacted each country across the globe, so that these first findings provide an insight into how community-based and institutionalised dementia care needs to receive a great deal of attention during the remainder of this pandemic, despite the commencement of vaccinations, with potential implications and learning for future pandemics or endemics.

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## Appendix 1. Interview schedule

- Q1. Has your situation changed since we last spoke?  
If you are caring for someone with dementia, has your caring situation changed?  
If you are living with dementia, have there been any significant changes in your life?
- Q2. What have been your experiences with social support services since the lockdown?  
Have services adapted better in recent weeks?  
If so, do these adaptations meet your needs?
- Q3. What are your experiences with remote support, whether digital or telephone?  
If you do receive remote support, does it benefit you?  
If you do receive remote support, what are your experiences using digital technology?
- Q4. Are you accessing any form of face-to-face support, and if so, what?
- Q5. Reflecting back on when support suddenly changed back in March, how are you coping now? Do you feel you have all the support you need?
- Q6. Is there anything else you feel is important to mention in terms of how COVID-19 has affected your ability to receive social support which we have not covered yet.